



October 26, 2018

Wendy Long, M.D.  
Director  
Division of TennCare  
310 Great Circle Road  
Nashville, TN 37243

*Transmitted via email to [public.notice.tennCare@tn.gov](mailto:public.notice.tennCare@tn.gov)*

**Re: Amendment 38 to the TennCare II Demonstration**

Dear Director Long:

On behalf of the 30 million Americans with one of the approximately 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) thanks TennCare for the opportunity to submit comments on Amendment 38 to the TennCare II Demonstration.

NORD is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. Since 1983, we have been committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services.

NORD appreciates Tennessee's stated goal of "improv[ing] health outcomes for individuals enrolled in TennCare."<sup>1</sup> However, after reviewing the proposal, we are concerned that Amendment 38 will threaten access to care for many within Tennessee's rare disease community.

**Tennessee's Proposal to Implement Work Requirements:**

We oppose the implementation of work requirements within TennCare for several reasons, the most basic of which being that work requirements do not further the goals of the Medicaid program or help low-income individuals improve their circumstances without needlessly compromising their access to care.

Further, this would increase the administrative burden on all Medicaid patients. Individuals will need to either attest to the number of hours they have worked or that they meet certain exemptions. Increasing administrative requirements will likely decrease the number of individuals with Medicaid coverage, regardless of whether they are exempt. Arkansas is

---

<sup>1</sup> Amendment 38 to the TennCare II Demonstration Pg. 1

currently implementing a similar policy requiring Medicaid enrollees to report their hours worked or their exemption. As of October 1, four months into implementation, the state has terminated coverage for 8,462 individuals and locked them out of coverage until January 2019.<sup>2</sup> An additional 12,589 individuals had one or two months of noncompliance and are at risk for losing coverage in the coming months.<sup>3</sup> Battling administrative red tape in order to keep coverage should not take away from patients' or caregivers' focus on maintaining their or their family's health.

Failing to navigate these burdensome administrative requirements could have serious – even life or death – consequences for people with rare diseases. If the state finds that individuals have failed to comply with the new requirements for more than two months out of a six-month period, they will be locked out of coverage until they demonstrate their compliance.<sup>4</sup> People who are in the middle of treatment for a life-threatening disease, rely on regular visits with healthcare providers, or must take daily medications to manage their chronic conditions cannot afford a sudden gap in their care.

We are also concerned that the exemptions to these requirements will not be nuanced or precise enough to avoid harming the health and wellbeing of Tennessee rare disease patients and their families. While the list of exemptions appears comprehensive, we can still easily envision many scenarios in which individuals with rare diseases or their caregivers will be unduly subjected to onerous and inappropriate work requirements. With a scarcity of physicians familiar with rare diseases and the prevalence of undiagnosed conditions, it is often difficult, even impossible, for rare disease patients to convey the extent of their symptoms on a standard form.

For example, it remains unclear from the given information within the proposal what would happen to caregivers of those with a rare disease. The Amendment notes that a beneficiary who is “providing caregiver services for a household member (child or adult) with a disability or incapacitation” would be exempt.<sup>5</sup> The Amendment does not say, however, how that would be adjudicated. It is not clear in this context what it means to be disabled. Consequently, it is not difficult to imagine a scenario in which this exemptions process would leave out a deserving caregiver.

Similarly, the Amendment proposes to exempt beneficiaries who, “are physically or mentally incapable of work, as certified by an appropriate medical professional...[or have] a short-term or long-term disability or an acute medical condition validated by a medical professional that would prevent them from complying.”<sup>6</sup> Yet, once again, the Amendment does not articulate how such a

---

<sup>2</sup> Arkansas Department of Health and Human Services, Arkansas Works Program, August 2018 and September 2018. Accessed at: <https://humanservices.arkansas.gov/newsroom/toolkits>.

<sup>3</sup> Ibid.

<sup>4</sup> Amendment 38 to the TennCare II Demonstration Pg. 4

<sup>5</sup> Amendment 38 to the TennCare II Demonstration Pg. 3

<sup>6</sup> Ibid.

determination would be made. It is not obvious from the Amendment what it will involve to have something “certified” or “validated” by an “appropriate medical professional.”<sup>7</sup>

Finally, TennCare’s “good cause” exemption is not sufficient to protect rare disease patients. In Arkansas, many individuals were unaware of the new requirements and, therefore, unaware that they needed to apply for such an exemption.<sup>8</sup> In August, the state granted just 45 good cause exemptions while terminating coverage for 4,353 individuals at the end of the month.<sup>9</sup> No exemption criteria can circumvent this problem and the serious risk posed to the health of the rare disease community.

These are just a handful of ways in which rare disease patients and their loved ones could slip through the cracks and lose access to their healthcare. In order to avoid the kind of delay or termination of care that could gravely impact the lives of Tennessee’s rare disease patients and their families, we urge TennCare to reconsider this provision.

NORD strongly believes healthcare should be affordable, accessible, and adequate. Amendment 38 does not meet that standard, and we urge TennCare to withdraw this proposal. Thank you again for the opportunity to provide comments.

Sincerely,



Tim Boyd  
Director of State Policy  
[tboyd@rarediseases.org](mailto:tboyd@rarediseases.org)



Terry Jo Bichell  
NORD Volunteer State Ambassador for Tennessee  
[terryjo.bichell@rareaction.org](mailto:terryjo.bichell@rareaction.org)  
[www.RareTN.org](http://www.RareTN.org)

---

<sup>7</sup> Ibid.

<sup>8</sup> Jessica Greene, “Medicaid Recipients’ Early Experience With the Arkansas Medicaid Work Requirement,” Health Affairs, Sept. 5, 2018. Accessed at: <https://www.healthaffairs.org/doi/10.1377/hblog20180904.979085/full/>.

<sup>9</sup> Arkansas Department of Health and Human Services, Arkansas Works Program, August 2018. Accessed at: [https://humanservices.arkansas.gov/images/uploads/newsroom/091218\\_AWRReport\\_Final.pdf](https://humanservices.arkansas.gov/images/uploads/newsroom/091218_AWRReport_Final.pdf).